

New Faces at ASCC

New faces are appearing at the Spinal Cord Commission these days. Not known for much turn over in staff, ASCC has experienced a change in staff in three positions over the past several months.

When you call the Little Rock Case Management office you may hear a new voice answering the telephone. **Mary Butler** began her duties as ASCC Case Management secretary in October. She has an Associate of Applied Science in Business Office Technology. Mary has a military background with over seven years experience as an administrative assistant. Besides her organizational skills she brings strong computer skills to the agency. Mary resides in Conway with her husband and two children and in her free time enjoys sewing and crafts.



ASCC welcomes new staff members: Russell Henry (left), Case Manager in the Batesville office, Mary Butler (middle), Little Rock Case Management secretary and Brad Barber (right), Case Manager in the Little Rock office.

Brad Barber also recently joined the Little Rock Case Management office. He is a graduate of Harding University with a degree in Social Work. Brad has a solid background in medical social work and case coordination and this experience

will be a definite asset to the Commission. His area will include parts of Pulaski and Saline Counties. This area was previously covered by Daniel Cook who is now the ASCC Intake Coordinator.

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Living With Spinal Cord Disabilities: New Challenges for a New Century

Mark your calendars for **Friday, June 2, 2000**. That is the date for our 2000 statewide conference. We will be returning to the **Ferndale 4-H Center** in West Little Rock this year to take advantage of their great conference space and wheelchair accessibility. The one-day conference will feature sessions on a variety of topics including new treatment options, accessibility and advocacy, recreation, vocational options and other pertinent issues. As always, we will have a full host of vendors and service providers in

the exhibit area, demonstrating new assistive technology and equipment.

The conference will also include a celebration of the 25th anniversary of the Arkansas Spinal Cord Commission. You will receive your conference registration brochure in April, which will provide additional information about specific speakers and sessions. So, mark your calendar and join us for a great day of learning, fellowship and fun!

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SPINAL COURIER

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ASCC accepts tax deductible donations. The generosity of the many individuals and families who over the years have made memorial donations is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at 501-296-1788/800-459-1517/ TDD 501-296-1794, or send your donation to:

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SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

MSAA Announces Home Modification Program

Dear Editor:

We have some exciting news! In the new year, the Multiple Sclerosis Association of America (MSAA) will launch a national home modification program. The program will attempt to help persons requiring home modifications to improve the quality of their life. These will include ramps, door widening, safety issues, and bathroom or kitchen modifications. If you know a person with MS who could benefit from a home modification, please

let us know as soon as possible. In addition, we are recruiting volunteers for this and other programs. MSAA will need volunteer assessors to go to the homes of persons with MS to assess their needs. We will also need volunteers who are handy with a hammer. If you can help us, please call us at 501-565-4722 today!

We hope to hear from you very soon, so that we can start the new millennium off with a bang . . . of a hammer.

Adam Roberts
MSAA Regional Director

From the Director

Whether you think the new millennium started on January 1, 2000, or doesn't start until 2001, you are probably having as much trouble as I am writing 2000 on everything. I'd been writing 19__ all my life. It's going to take me a little while to get used to it!

The new year marks an important milestone in the history of the Arkansas Spinal Cord Commission—it is our 25th birthday. The legislation which created the Commission was enacted in 1975. In the past twenty-five years, we have provided services to nearly 5,000 people with spinal cord disabilities and their families, with over 2,000 still on our active rolls. We run the oldest and most comprehensive spinal cord disability registry in the nation and continue to work closely with hundreds of physicians, social workers, nurses and other health care providers to assure that all spinal cord disabilities are reported to the Commission within five days of identification. I could go on and on singing our laurels, but really, the credit goes to **Jane Smith**, who had the vision of what comprehensive SCI care should be, and to people like **Maurice Smith**, **Steve Flanigan**, **Harold Thomas**, **Russell Baxter** and **Shirley McCluer**, who helped her make it a reality! In the past twenty-five years many things have changed the lives of those of you who live every day with spinal cord disability, but I hope the one thing that hasn't changed is that the Commission and our Case Managers are always here to help where we can. Join us in our birthday celebration and Happy New Year!

Cheryl Vines

PS: If you would like to read more about the history of the Spinal Cord Commission, ASCC Fact Sheet #29 is available on our website or by contacting the McCluer Resource Center.

Accessibility at the New Alltel Arena

by Mike Long

For my 50th birthday, my wife Marsha treated me to the Elton John concert at the new Alltel Arena. With all the publicity about construction problems, we weren't sure the show would go on, but it turned out to be a fabulous evening. The audience had a good time as Sir Elton sang for almost three hours, and we showed our appreciation with many standing ovations. Of course, some of us had to stand in spirit only, but it counted just the same. What a way to officially open the new arena!

With this limited one-time experience, I want to share my impression of the accessibility of the arena. First, the accessible parking we used is in the adjacent lot just south of the arena, toward the river. We had to drive around a little to get to the lot entrance and past the traffic officers, but we were early and had planned for such contingencies. The only approach to the accessible lot is from the west on Washington Avenue. Although there are marked accessible parking places, the parking attendants guide you to an appropriate space, which may or may not be marked. In our case they were going to place a cone to block an accessible aisle for my ramp, but Marsha was driving and we did not need it. Incidentally, the lot is also used for VIP

parking as well, so it is not ours exclusively.

The entrance to the arena from the lot is a ground level tunnel directly across the street. Since the street is not open to through traffic, crossing is not a problem. Inside, we rode the elevator up to our designated level. The arena guides were confused about the location of the accessible ramps leading to the seating area, but after one false start, we got to our seats. It is my understanding that there is wheelchair seating on the floor, in the mid-level section where we were, and in the upper section, too.

We were sitting just in front of the sky boxes. There are several rows on each side of the arena set aside for wheelchairs, with folding chairs provided for attendants. Ramps at each corner of the arena lead from the concourse and concession area to the seats. All in all, I thought our seats were great. By the way, TicketMaster originally sold Marsha tickets for the floor. She exchanged them when she realized that I would not be able to see the stage when folks in front of us were on their feet, which they certainly were much of the evening.

Unfortunately, that is the extent of my experience at the new arena. I

did not try to access the other sections, nor did I use any of the restrooms. However, when ASCC Case Manager Martha Henderson asked me to write this article, I promptly called to arrange to tour the arena so I could provide a comprehensive report. I explained what I wanted, and the Alltel person I talked with promised to give my request to the office manager. I never heard back from anybody, but I was not surprised.

In previous discussions with **Cliff Coates**, he told me there are some outside grades that are too steep associated with parking spaces right next to the arena itself, which are supposed to be corrected. These are not in the lot where we parked. He also told me that access to the toilets meet ADA requirements but are difficult to use if you need to side transfer, and there are apparently a few other glitches, too.

Marsha and I are excited about having the Alltel Arena in our city. We encourage each of you to go check it out for yourself. There will be lots of great concerts and events for our entertainment. In fact, I already have plans to go see Katarina Witt in the ice show when she comes to town this winter. Like my dear wife, she is such a darkhaired beauty. Oops! I got sidetracked.

White County SCI Support Group Enjoys Massage Therapy

On November 2, participants in the White County Support Group were treated to massage therapy with **Justine Beal**, a therapist in Searcy. The support group was offered the opportunity to have this special session through **Todd Price**, White County Memorial Hospital Liaison. Those who wanted to have their back or legs massaged, were advised to wear sweats or other comfortable clothes.

Justine began the session by explaining what massage therapy is

and is not. She pointed out that while a massage is relaxing and makes a person feel good, the purpose of massage therapy is to work the five muscle groups to relieve pain and stress. "In fact," she said, "sometimes massage therapy does hurt as you go deeper into the muscles, but a therapist knows how to gradually work the muscles so the result is reduced stress and pain."

A member of the group who has had therapy for many years echoed

this. "I would not be able to use my hands the way I do, if I had not had massage therapy." Each person in the group had an opportunity to have a shoulder rub, back rub or leg rub—all were convinced of the value of massage therapy.

All persons with spinal cord disabilities are invited to attend the monthly SCI support group meetings that meet from **10:30 a.m. to noon on the first Tuesday** of each month at White County Memorial Hospital.

How Close Is a Cure for SCI?

An Interview with Wise Young, MD

Part 2

University of Washington Rehabilitation Department, Spinal Cord Injury Update interviewed internationally renowned research scientist Wise Young, MD, PhD, director of the Neuroscience Center and the Spinal Cord Injury Project at Rutgers University. In Part 1 (reprinted with permission in the October 1999 issue of Spinal Courier), Young described current avenues of nerve cell regeneration research taking place around the world. Following is the second, and final, installment.

Q: You have predicted that effective treatment for SCI will be available around the year 2003. How did you arrive at this time frame?

A: Christopher Reeve asked me two years ago how long it would take for the first treatments for chronic spinal cord injury to be available for people. At that time, I told him that it would take a minimum of seven years. Christopher said that we should make seven years the goal. It is important to understand that the seven-year time is a goal and not a prediction.

Many obstacles lie in our path to a cure. The foremost obstacle is the limited funds that are available to develop and test therapies in clinical trial. At present, there is limited industry interest in finding a cure for SCI. The NIH (National Institutes of Health) is funding about \$60 million of SCI research a year; most of this research emphasizes basic mechanisms of cell injury and growth.

Clinical trials are not guaranteed to succeed and each may take 3-4 years to complete. Every trial is like a throw of dice; ideally, a

clinical trial has a 50% chance of yielding a positive result. To ensure that we have a "hit," we must do many parallel trials. For example, the probability that we get an even number on a dice throw is 50%. We may have to throw the dice several times to get an even number. However, if five people were to throw the dice at the same time, the probability that we will have one or more even numbers is virtually certain.

We therefore have to push hard for many groups all over the world to throw the dice. This will require at least a doubling of the current funding level for SCI research from government, private foundations and industry. If we are able to get five clinical trials going by 2000, I believe that we have a good chance that one or more will be successful. That is the basis of the goal.

Clinical trials are not guaranteed to succeed. Every trial is like a throw of dice; . . . To ensure that we have a "hit," we must do many parallel trials.

Q: How long before treatment will be widely available for people with new injuries as well as those with long-standing SCI?

A: The first therapy that improves function in chronic SCI will probably be a drug called 4-aminopyridine (4-AP). A clinical trial is currently being carried out

to determine whether 4-AP improves function. If the results are positive, this trial may lead to limited FDA approval. If so, the drug may become available before the year 2000.

If the current studies of IN-1 and L1 (see Part 1 of this interview, October 1999 issue) show that these are safe therapies, they may go into clinical trial by 2000; if so, it will take three years for the trials to be completed. If either of those turns out to improve function in humans, the first regenerative therapies may be available by 2003. We currently don't have an answer to the question of whether any of these therapies work for people who have had their injuries for many years. However, I believe that we have the tools to kick start cells to grow again in the spinal cord. After all, we know that cells will begin growing after an injury and therefore have been systematically studying the spinal cord to find out what triggers the growth of these cells.

Q: One hears claims of successful procedures and treatments, such as shark fetal cell transplants and omental transplants, that are only available outside the United States. Why aren't these procedures being studied in this country? How can a layperson know which new SCI treatments are legitimate and which are "bogus"?

A: While we should not dismiss these therapies, most of the claims for them are not based on convincing scientific data. Therapies must be tested in rigorously controlled clinical trials in which subjects are randomly assigned to receive either

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Wise Young - Part 2

Continued from page 4

the experimental therapy or standard therapy for comparison. Both the shark embryo and omentum transplant therapies involve surgery.

Unfortunately, it is difficult to do controlled clinical trials with surgical therapies because it is hard to operate on somebody and not do anything. The only approach is to compare two surgical therapies. Unfortunately, none of the groups studying these therapies has attempted a rigorous comparison between decompressive surgery with shark embryo or omentum transplants and surgery that simply decompresses without transplants. Of course, all treatments must be judged by the risks and benefits that they offer. Because both shark embryo and omentum transplants involve invasive surgery, the risks are not trivial. To my knowledge, the benefits have been modest and not yet convincing. Doctors who push unproved therapies are not

necessarily evil or bad doctors; they may truly believe that their therapies work and that they are helping their patients.

There are several telltale signs of unproved therapies. If a person or family is considering an experimental therapy, the following are

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simple and commonsense things to do:

1. Ask whether the claimed treatment results have been published in a peer reviewed medical or scientific journal. Most journals require rigorous proof of efficacy before they allow a claim to be published.

2. Be wary of people who ask for a lot of money for an experimental therapy. A common asking price for unproved therapies is \$50,000-\$100,000. Most legitimate clinical trials will not ask for large payments for unproved therapy. Generally, if a therapy has a great deal of promise, the therapy trial will be supported by a company or an NIH grant.
3. Investigate the risks. Most therapies have risks. Carefully weigh the risks and benefits of the therapy. Many people believe that they have nothing to lose. Everybody has something to lose.

The Spinal Cord Injury Project can be reached at Neuroscience Center, Rutgers University, 604 Allison Rd., D413, Piscataway, NJ 08854-8082 (732-445-6573, 445-2061; SCIPProj@biology.rutgers.edu).

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Habitat for Humanity Builds Accessible House

Two years ago, **Larry Berry** applied for housing through Habitat for Humanity (HFH). This would be the first "accessible" home built in Arkansas by Habitat. To qualify for a home, an individual must put in 200 hours of "sweat equity" (work on current Habitat homes for others). A family must have 400 hours, so Larry and his wife, Wanda, began working in 1997. By November 6, 1999, they were ready to begin their house.

Larry was delighted that a lot was for sale across the street from where he was living. HFH purchased the lot and the work began. Three construction workers from Habitat and many volunteers began what is called a "blitz build," and the house was completed in two weeks. Larry and his family have



Larry Berry enjoyed working on his new accessible Habitat for Humanity home.

moved into their four bedroom home with adequate space and complete accessibility.

Corporate sponsors donate money to buy land and building supplies. Local sponsors are sought for each

house to assure there will be enough volunteers. Fellowship Bible Church sponsored the Berry's house, and some days there were thirty or more volunteers working. Other volunteers from the church provided lunch and drinks under a canopy nearby.

Pulaski County Habitat for Humanity has been here ten years and has built more than 25 houses. When asked if they ever needed more volunteers, a Habitat for Humanity employee said they always had plenty—they just need more people who want to build a house themselves. If you are interested in building a house or being a volunteer, call Pulaski County Habitat for Humanity at **501-376-4434** or the national HFH office toll-free at **800-422-4828**.

Folic Acid — for Everyone, Even Men !

It's been well established that women who take folic acid, beginning before conception and continuing into the first month of pregnancy, can reduce the risk of having a baby with certain birth defects of the brain and spine called neural tube defects. That's great for women of childbearing age, their babies and the dads. But how about everybody else? If you're an adult woman who can't get pregnant or a man, should you be concerned about taking folic acid?

In recent years, researchers have come to realize that folic acid is very important for everyone in maintaining health, including men. It has long been known that folic acid plays an important role in production of normal red blood cells, and that individuals who are deficient in folic acid sometimes developed a form of anemia called megaloblastic anemia (characterized by a reduced number of red blood cells.) More recent studies suggest that folic acid also may help prevent heart disease and stroke.

"We don't have a clinic trial, but the totality of the evidence is strong that folic acid can lower the risk of heart disease," says the University of Washington's Shirley Beresford.

It all started in the 1960s, when researcher Kilmer McCully, then at Harvard Medical School, found clogged arteries in children and infants with a genetic defect that sent their levels of an amino acid called *homocysteine* through the roof. Excess homocysteine, he reasoned, is toxic to blood vessels.

Most scientists ignored McCully's theory. Not any more. Since then, researchers have found that:

- People with higher levels of

homocysteine in their blood have a higher risk of heart disease and stroke.^{1, 2}

- People who consume more folate or have more in their blood—usually from taking a multivitamin—have lower homocysteine levels.³

- In two studies—one of 5,000 Canadians and one of 80,000 U.S. nurses—those who reported eating diets high in folate had a

lower risk of heart disease over the next 15 years.^{4,5}

The only thing that's missing: a clinical trial.

A few are under way. For example, the Vitamin Intervention for Stroke Prevention trial is testing whether low or high dose mixtures of folic acid and vitamins B-6 and B-12 can cut the risk of a second stroke in people with high homocysteine levels. (B-6 and B-12 also lower homocysteine though the evidence is strongest for folic acid.)

You can wait for the trials, or you can take a multivitamin with 400 mcg (microgram) of folic acid now. That's the amount that appears to lower homocysteine sufficiently. And because it's the Daily Value (or U.S. Recommended Daily Allowance), it's also the level that millions of Americans already take in their multivitamins.

"Taking a supplement with 400 mcg of folic acid to reduce the risk of heart disease is prudent," says Beresford.

Is it safe? Some researchers worry that taking too much folic acid could mask a vitamin B-12 deficiency in seniors. But seniors can dodge that (theoretical) bullet simply by taking B-12. Many of them need it anyway.

So all adults, including men, have plenty of good reasons for taking folic acid.

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¹ J. Amer. Med. Assoc. 268: 877, 1992.

² New Eng. J. Med. 337: 230, 1997.

³ J. Amer. Med. Assoc. 270: 2693, 1993.

⁴ J. Amer. Med. Assoc. 275: 1893, 1996.

⁵ J. Amer. Med. Assoc. 279: 359, 392, 1998.

New Faces

Continued from page 1

Those of us in the Little Rock office have learned quickly that Brad is an avid Razorback fan and loves outdoor activities. He does however have a secret desire to attend culinary school one day and become a world famous chef.

Russell Henry assumed the responsibility of the ASCC Batesville Case Manager that has been vacant since the retirement of Charles Crowson. Since the latter part of September he has been making his way across the ten county area meeting as many clients as possible. Russell received his Master of Rehabilitation Counseling degree from Arkansas State University. His previous experience has been in the area of substance abuse and rehabilitation.

Russell is an outdoorsman who loves hiking, camping, target shooting and photography. He looks forward to spending time getting to know the individuals in his area and perhaps snapping a few shots along the way.

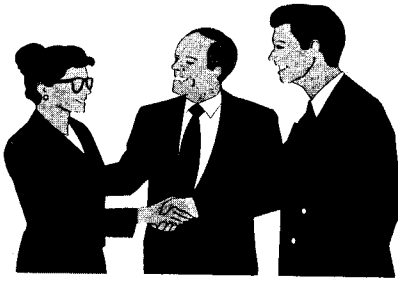
The Commission members and staff of ASCC feel fortunate to have such qualified individuals joining our agency. Welcome aboard, Mary, Brad and Russell !

Successful Self-Advocacy

Ever run into a problem getting the benefits or services to which you **KNOW** you are entitled?

Ever get the run-around on important issues?

These are the times when a short course in self-advocacy would come in handy. After all, you don't want to rely on other people to take care of your problems forever.



Self-advocacy is the active support of an idea, cause or policy in one's own behalf. It is a simple process, but it is one that is not practiced much. This may be because it is difficult, and often scary, to stand up to agencies that have such power over our lives.

To help you better prepare yourself when facing a difficult situation, the Disability Rights Center has created an outline of the key steps to successful self-advocacy. It is important to remember that, if you want to be an effective self-advocate, you must be organized, flexible, objective and persistent. You must be prepared to deal with responses such as, "We can't," "We don't have the money," and "We know what's best."

A. Identify Needs

1. What services do you want: education, medical care, housing, employment, transportation?
2. Who can provide the services you need?
3. What do you need to get these services?

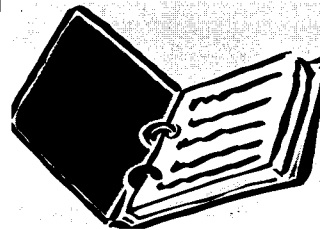
B. Influence Decision Makers

1. Build a good relationship with the person working directly with you.

2. Come to meetings **prepared to be positive**. Smile and be friendly. Leave resentment and defensiveness at home.

3. Get to know the people who can make decisions. **Keep names, addresses, phone numbers, etc.**, so that you can contact them for help and information.

4. **Know your rights**. Few people know all the laws that concern services, but it is important to know where to get information about your rights. Contact local advocacy groups, parent support groups, state agencies and the protection and advocacy agency funded by the federal government and ask to have your rights explained. If you can, get the explanation in writing.



5. Be aware if the agency's **services** are offered on a **mandatory or permissive basis** and if you, your child or family meets the eligibility criteria. What information do you need to qualify your request for service? What is the agency's application process? What is the appeal process if services are denied?
6. **Develop good communication skills**. It is just as important to know how to say something as it is to know what to say. Good communication includes give and take and knowing how to develop a positive relationship, to see issues from the agency's side.

It also includes **being assertive**. Assertiveness simply means standing up for one's personal rights and expressing them in an appropriate way, while still **respecting the rights and opinions of others**.

C. Keep a Paper Trail

A paper trail means **keeping written records** of events or decisions that affect your efforts to get services. Keeping written records of what went on and when is often crucial in backing up your position. Paper trail skills include letter writing, note taking and record keeping. Keep a record at home of reports and notes relevant to you. Ask for a written statement of what action will be taken and when the action will begin.

D. Follow Up

Follow up to make sure that the services you worked hard to get are being delivered. Self-advocacy is a cycle. Self-advocates must reassess their needs and the services available to meet their needs on an on-going basis. Each stage in the cycle means new needs, new decision makers to influence and new follow up visits. **Being an effective advocate demands persistence and patience.**

(Adapted from A Parent's Guide, Civil Rights/Education, published by the Disability Rights Center, Inc. Used with permission, courtesy of Jan C. Baker.)

For more information regarding self-advocacy, contact the Disability Rights Center at 1100 N. University, Suite 201, Little Rock, AR 72207; phone **501-296-1775** or **800-482-1174** (V/TTY)

New Items in the McCluer Resource Center

The McCluer Education and Resource Center on Spinal Cord Injury has added a number of new items to its collection. If you are interested in checking out any of the resources, please call the Resource Center at (501) 296-1792 or (800) 459-1517. Some of the new additions include:

- **Janweck E-Z Autolift** (video), by Janweck Enterprises, shows a demonstration of the behind the seat lift for cars and third-door trucks.
- **Parenting a Child with Special Needs: A Guide to Reading and Resources** (booklet), by the National Information Center for Children and Youth with Disabilities, contains articles,



resource listings, relevant organizations' contact information and a list of publishers to assist parents in finding the information they need.

- **Questions and Answers about the IDEA** (booklet), by the National Information Center for Children and Youth, includes information on the background of the IDEA, accessing services, the IEP, additional resources and definitions of disabilities.

Junior Rollin' Razorbacks Fourth in Tournament

The Junior Rollin' Razorbacks placed fourth against the top teams in the nation at the November 20 and 21 Regional Qualifying tournament in Hot Springs. In the first game, the Razorbacks matched up against Kansas City, winning by one point, 41-40. In the second game the Razorbacks fell short to St. Louis, losing 41-29. Arkansas then played Kansas City again and won, 49-26. Arkansas lost the final game to Lakeshore, Alabama, 70-43, putting the team fourth overall in the tournament. **Ryan Buchman** was named team most valuable player. **Tyler Garner**, **Tadd Crowe** and **Jeremy Fisher** were named to the All-Tournament Defense Team.

In the 8 1/2 foot division (ages 12 and under), **Justin Crawford** was named to the All-Tournament Offense Team and **Mary Allison** was named to the All-Tournament Defense Team. The Arkansas Ball Hawks placed third in this division.

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